

THE ROLE OF MATERNAL DEPRESSION IN ACCESSING EARLY INTERVENTION SERVICES FOR CHILDREN WITH DEVELOPMENTAL DELAY

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ABSTRACT

**SIOBHAN EILEEN COLGAN: The Role of Maternal Depression in Accessing Early Intervention Services for Children with Developmental Delay
(Under the direction of Julie Daniels)**

This study investigated the relationship between maternal depression and children's access to early intervention services among a sample of children with developmental delay at age two who were determined to be eligible for early intervention services, were full term and of normal birth weight, and were not previously identified with any special needs in infancy (n=600). The investigation utilized data collected as part of the Early Childhood Longitudinal Study-Birth cohort (ECLS-B). Children were determined to be eligible for early intervention services based on: the child's degree of delay on a standardized measure administered by ECLS-B at age two; the state the child lived in; and the criteria for eligibility for early intervention in the child's state. Descriptive and logistic regression analyses examined 1) the proportion of sample children's mothers who reported that their child had a disability or special need, 2) the association of identification of special needs and maternal depression, and 3) the relationship between maternal depression and the child's receipt of early intervention services.

Results showed that 11.3% of mothers reported being told that their child had any special need or condition. Logistic regression analysis found that mothers with depression were significantly more likely than those without depression to report that their child had a disability (adjusted OR=1.75 [95% confidence interval CI 1.65-

1.83]). The final analysis investigated receipt of early intervention services, and found that 5.9% of the sample received any early intervention services. Adjusted logistic regression results showed maternal depression was associated with a slightly increased probability of acquiring early intervention services (adjusted OR=1.14 [95% confidence interval CI 1.07-1.20]). In both logistic regression analyses, odds ratios were adjusted for child's race/ethnicity, SES quintiles, mother's partnered status, the child's mean developmental t-score, maternal age, and the number of well-child visits.

While maternal depression was associated with both increased identification of the child's special need(s) and increased access to child intervention services, results from the investigation demonstrate an overall pattern of young children with developmental delays being overwhelmingly under-identified by parents and physicians, and under-served in the early intervention system.

DEDICATION

To my father, who inspired in me a love of learning
and who quietly assumed greatness- you are missed.

And to my daughter, who keeps me grounded in
child dynamism, this is for us.

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CHAPTER 1: INTRODUCTION

It has been estimated that about 13% of children younger than age three in the U.S. have developmental delays that make them eligible for early intervention services (Rosenberg, Zhang, & Robinson, 2008). Research has shown that not all children who may be eligible for early intervention receive services (Rosenberg et al, 2008, Feinberg, 2011). Parents may need to navigate multiple systems of service delivery is to determine whether their child is eligible and if they are, to access services. These may include health care systems, state early intervention programs, local nonprofit agencies, and/or parent support or referral agencies, among others. These systems vary among states, and often within states as well. There are, therefore, multiple pathways and potential detours in the processes through which parents travel from parental concern to identification of delays, eligibility determination, through the onset of early intervention services. In addition, some states have moved towards more restrictive eligibility criteria due to limited resources and capacity, so efforts to find and refer children with potential needs may be restricted by geographic isolation, cultural barriers, access to appropriate screening, and early identification resources, among other reasons. Despite myriad barriers, evidence is strong that intervention in the early years provides direct benefits to children and families across multiple domains of child development, readiness for school, and parent-child interactions.

In order for children to receive intervention services, several pathways to getting services are considered “typical”. Some types of disabilities will be identified at birth or shortly thereafter due to medical indications, newborn screenings, or problems with infant growth. For others, problems become apparent later and parents are often the first to notice; they may then voice concerns to family members, physicians or other professionals. The current study focuses on young children with developmental delay that is not identified in infancy, and the parental characteristics related to those children entering early intervention services. This study examines several aspects of the parent’s role in accessing early intervention services for children who are developmentally delayed and likely eligible for services in their state. The specific focus is on the role of maternal depression as it is associated with maternal report that their child has a developmental delay, and in getting children with developmental delays into early intervention services.

Presence of depression in a primary caregiver has been shown to have myriad impacts on a child’s development, including poorer cognitive and language outcomes, social emotional development, and greater risk for affective disorders later in the child’s life. Impacts on the mother include impairments in capacity for every day and routine tasks, poorer overall physical health, altered emotional responses, and secondary impacts on occupational status and social involvement in the family and community. This study investigates the role of maternal depression among families with a child with a developmental disability by addressing the following research questions:

1. Among children with developmental delay at two years of age, what proportion of mothers report that the child has special needs?
2. Among children with developmental delay at age two, does a mothers' report that the child has a special need vary according to the presence of maternal depression?
3. Among children with developmental delay at two years of age, is the presence of maternal depression associated with receipt of early intervention services?

CHAPTER 2: LITERATURE REVIEW

This chapter provides a summary of literature related to the current study assessing parental predictors of children with developmental disabilities getting services. After presenting a theoretical framework, the review is divided into three main topical areas: research on the relationship between childhood disability and maternal depression, parental identification of disabilities in young children, and research demonstrating the importance of timely intervention for young children with disabilities. The chapter then summarizes the existing program and policy context related to child find and eligibility for early intervention for children with disabilities from zero to three, and the philosophical orientation of early intervention services as a family-centered approach. The chapter concludes by revisiting the research questions in light of the current knowledge base and summarizing the rationale for the current study's topic of investigation.

The early childhood period from birth to five is a time of complex and intense development for children across multiple developmental domains. The National Research Council (NRC) (2000) report on child development discusses the importance of the underpinnings of brain and neurological development, emphasizing three main areas of accomplishment for early childhood. The first area involves transitioning from external to internal regulation of emotions, attention, and behavior, including development of skills such as learning to comfort oneself and beginning to identify and monitor emotions. Second, children are acquiring the skills

and capacity relate positively to others, including forming secure attachments to others, negotiating conflicts, and developing peer relationships. The third accomplishment of the period from birth to five includes development of the foundations of learning and communication, such as acquiring language, problem solving, and reasoning skills. To understand these processes, a contextual framework is presented, explaining the interplay among the multiple domains of development and considering environmental influences at the family, community, and broader societal levels.

Theoretical Foundation

One framework for grounding the current study is the unified theory of development described by Sameroff (2010). This perspective explains development as integration of nature and nurture, and incorporates four models of development: personal change, contextual, regulation, and representational models. Sameroff explains a cyclical evolution throughout child development scientific research history, with alternating emphases between biological explanations and pathways (nature) and individual and family systems interaction variables (nurture). The following quote provides an illustration of the conundrum of the nature-nurture explanations as it relates to child development research:

“Practically, the nature-nurture question comes into play when a child has a problem and the question arises, “Who is responsible?” Most parents’ first response is to blame the child and most professionals’ first response is to blame the parents. However, most scientists know that it is both. It is both child and parent, but it is also neurons and neighborhoods, synapses and schools, proteins and peers, and genes and governments. But that conclusion does not explain how it is both.”
Sameroff (2010) p.7

Towards the end of providing a sufficiently complex framework for understanding the myriad processes and interactions involved in young children's development, the four models of understanding development outlined by Sameroff are described, which together constitute his unified theory.

The first is the personal change model, which serves to explain early developmental growth via stages and maturation. The model explains development as a series of increasingly complex competencies beginning in infancy with early attachments and sensory-motor functioning, and subsequently becoming more complex over time. This model reflects personal change or growth as a multi-stage process, with series of developmental milestones throughout early childhood.

The contextual model is the second contributor to the unified theory. This model is exemplified by Bronfenbrenner (1979), who described a social ecological system detailing multiple social systems (e.g. families, childcare, communities) and their influences upon child development. Children's interactions in the microsystem (the child's face to face interactions with the mother and immediate family (or primary caregivers)) are considered to be bi-directional and reciprocal, with the child an active participant in the interactions. Within this system, interactions may be altered due to the child's interaction style or ability, the mother's, or both. With a communication dyad of a young child with developmental delays and a mother with an affective disorder such as depression, the potential for reduced frequency, intensity, or less positive interactions may be increased. These interactions also overlap with the other systems, encompassing parental interactions with medical providers, extended family, and child care settings (the mesosystem); and the

family's neighborhood, work and social networks (the exosystem). This contextual model also acknowledges the influence of cultural subgroups or customs and the broader geo-political context (macrosystem) as well as changes over time (chronosystem). The geopolitical context would include laws and policies related to accessing public services such as early childhood special education, Part C services, or Medicaid, and customs related to one's social class.

The third model described by Sameroff is the regulation model, which goes beyond self-regulation to include "other-regulation", or the surrounding context actively involved with the self. Self-regulation is therefore ultimately highly dependent upon external ("other") regulators. As a child's self-regulation capacity increases, the role of the other decreases, moving the child from predominantly biological processes to social and psychological; among young children, this increased capacity primarily occurs through others' actions (Sameroff & Fiese, 2000). Sameroff (2011) further categorizes these shifts between other-regulation and self-regulation as transactional in nature, such that there are bi-directional effects between the child and his/her environment.

The fourth and final model described in the unified theory is the representational model, which reflects that children's thoughts are translations of their experiences, which then provide a blueprint for interpretation and encoding of additional experiences. Cognitive, social, and cultural representations are included, such that "the order or disorder of a family or society's representation of itself affects the adaptive functioning of its members" (Sameroff, 2011, p. 17).

Sameroff incorporates the four models of development to reflect the myriad interacting biological and psychological processes. Together these construct a unified orientation to explaining developmental processes, operating within a “biopsychological” self-system. Social systems are interacting with biological processes including neuroendocrinology, genomics, and neurophysiology, among others; and psychological processes include mental health, social competence, identity, and other emotional and cognitive domains. The personal change aspect to the unified theory reflects increasing growth and development over time, with the biological and psychological aspects small during infancy and increasing throughout childhood into adulthood.

The overarching recommendation with respect to research and application of research findings is for researchers to maintain a top-down approach, aiming to preserve the perspective that they are only investigating a part of a whole, a whole that encompasses various engaged, interacting systems. Sameroff asserts the integrated theory he presents addresses a “contemporary zeitgeist” in research that is trending toward more dynamic interpretations of findings, and towards increasing the relevance of research that may be used to alter outcomes for children.

The models and unified theory outlined above ground the research topic of maternal depression and access to children’s early intervention services. The depression component itself consists of biological, psychological, and social aspects, as do children with developmental delays. While the social-ecological subsystems described by Bronfenbrenner are incorporated to some extent through analyses of socioeconomic measures, family demographics and policies related to

eligibility for early intervention, among others, these are clearly a small snapshot of the multiple interactions at work related to answering the current research questions. The remainder of the chapter provides an overview of research relevant to the current study.

Maternal Depression Overview

A recent meta-analysis of multiple studies found estimates of major and minor depressive disorders ranging from 6.9%- 12.9% at different periods throughout pregnancy and the first year postpartum (Gavin, Gaynes, Lohr, Meltzer-Brody, Gartlehner & Swinson, 2005). The review reports combined prevalence of 19% in the first three months postpartum, with the criteria being diagnosis of a depressive disorder according to the DSM criteria. When looking at depressive symptomology alone, results from the ECLS-B study found that among mothers of 9-month old children, 59.1% scored as non-depressed, 24.7% had mild depressive symptoms, 9.7% had moderate depressive symptoms, and 6.5% had severe depressive symptoms (Huang, Wong, Ronzio, & Yu, 2007).

Depression affects individuals across all racial, ethnic, and socioeconomic groups, although some differences have been reported among subgroups. Using data from mothers of 9-month old children collected in the ECLS-B study, results show mothers born in the US were more likely to report depressive symptomology in all race and ethnic groups except Pacific Islander, as compared to foreign-born mothers, with non-Hispanic black women reporting the highest rates (Huang, et al., 2007). The study also showed that low income and teenage mothers reported higher

rates of depression, as did mothers living in rural areas. Among mothers with moderate to severe symptoms, foreign-born and minority mothers with depression were also less likely to consult a physician and to think they needed consultation than Caucasian mothers.

Several studies have shown significantly higher rates of depression among mothers of children with a range of disabilities when compared to mothers of children without a disability (Witt, Riley & Coiro, 2003; Veisson, 1999; Yim, Moon, Rah & Lee, 1996; Harvey, O'Callaghan & Vines, 1997). Still other research has reported comparable, yet high, rates of maternal depression symptoms among mothers of children with and without disabilities, including rates of approximately 50% among mothers of infants (Gowen, Johnson-Martin & Applebaum, 1989) and 23-33% across the first year postpartum for mothers of children with and without Cerebral Palsy (Lambrenos, Weindling, Calam & Cox, 1995).

Differential rates of depression among different studies are in part reflecting differences among the measures used for classifying depression. The main difference between types of measures concerns whether the tool is classifying 1) symptomology indicating a depressed mood or stress condition or 2) a diagnosable disorder according to common mental health or psychiatric criteria. Many studies reporting high percentages of women with depression used the Center for Epidemiological Studies' Depression Scale (CES-D), a self-report measure of depressive symptomology for use in the general population (Radloff, 1977). The CES-D is not a diagnostic tool, and the items and scoring on this scale do not correspond to a clinical diagnosis of a depressive disorder. More restrictive

measures such as the depression measure used in the current study (the CIDI-SF) have been developed to estimate clinically significant impairment and correspond to medical or mental health diagnoses. This latter group of measures, due to a more restrictive standard, will yield fewer cases meeting the criteria of “depression” than a scale more generally assessing depressive symptomology.

Correlates of Maternal Depression

When measured over the course of early childhood, more severe and chronic postpartum depressive symptoms in mothers are associated with poorer language outcomes and increased behavioral problems in children at age five (Brennan, Hammen, Andersen, Bor, Najman, & Williams, 2000). In a longitudinal study of mothers of infants with and without disabilities, different mothers reported high levels of depression at different time points in the study (Gowen et al, 1989), underscoring the need to assess both current incidence and prior history of depression.

A number of studies have assessed factors related to depression among mothers of children with disabilities. Olsson & Hwang (2001) found single mothers of children with autism and mental retardation had more severe depression than married mothers did, although the overall rates of depression (including mild and severe) did not differ based on marital status. Marital satisfaction, relationships, and spousal support are also seen as moderators of risk for maternal depression among children with developmental disabilities (Glidden & Floyd, 1997), as are greater religiosity and internal locus of control (Friedrich, 1988). Maternal mental health problems are also associated with poverty (Emerson, 2003; King, King, Rosenbaum & Goffin, 1999), poorer overall family functioning (Emerson, 2003; King, et al, 1999),

and less family support (King, et al, 1999) among mothers of children with disabilities. With regard to interaction styles, studies show depressed mothers to demonstrate more frequent sad, irritable, and punitive behavior than mothers without depression (Goodman & Gottlieb, 1999). Children with existing disabilities or delays may be especially vulnerable to negative effects of these types of interaction styles.

Individuals with developmental disabilities are also reported to experience poorer mental health outcomes themselves, including affective disorders such as anxiety and depression. These typically emerge later in adolescence and adulthood, and may indicate a biological risk profile (heritability), secondary effects of core cognitive, social, or communicative impairments, or interaction and coping styles learned from parents with mental health issues themselves (Goodman & Gottlieb, 1999).

Identification of Disabilities in Young Children

Identification of developmental delay in young children relies on parental report about the child's skills and behavior along with expert clinical knowledge and observation. Parents are usually the first to notice something may not be right with the child's development, and have been found to provide reliable information about their children. For many children, the avenue through which they are identified for delays is via routine preventive care such as well-child check-ups. Physicians serving young children may utilize formal screening instruments, observe child motor and milestone development, and/or prompt the parent about any concerns s/he has about the child's development. One large-scale study found mothers who were depressed at two to four months postpartum to have different patterns of health care

use for their children. At age 30-33 months, children whose mothers were depressed had had fewer preventative care visits, were less frequently up-to-date on preventative vaccinations, and used acute care (e.g. emergency rooms) at higher rates than mothers without postpartum depression (Minkovitz, Strobino, Scharfstein, Hou, Miller, Mistry, et al. 2005).

In one report using the ECLS-B data, maternal depression was assessed among a broadly defined group of children with special needs, including children with disabilities or conditions identified at birth and low birth weight children (Feinberg, 2010). Among this group, children of mothers who had depressive symptoms were approximately four times more likely to have received early intervention services. The current study complements the Feinberg study by focusing on a specific population of children with developmental delays that did not have a previously identified diagnosis (i.e. did not have a diagnosis at birth or in infancy), as well as focusing on mothers with clinically diagnosable depression, vs. elevated symptoms. Children with developmental delay, the subgroup of interest in the current study, may be a more difficult subgroup to identify by both parents and physicians and therefore more susceptible to the effects of maternal mental health issues.

Effectiveness of Early Intervention

High quality early intervention services have been shown to improve outcomes for children, families, and communities. Outcomes for young children with disabilities include positive impacts across developmental domains, including health, language/ communication, behavior, and social/emotional development. Families

benefit by learning skills to better meet a child's special needs from an early age and services designed to support and positively influence the family beyond the focal child. Community benefits include children's future academic success, a decreased need for special education and increased participation in the work force and community. This section highlights research on these and other benefits of intervention for children from birth to age three, from the National Early Intervention Longitudinal Study (NEILS) and other research.

Impact of Early Intervention on Child Outcomes. Among children in the NEILS study, a nationally representative study of children with disabilities participating in Part C early intervention, child outcomes at 36 months included increased motor, social, and cognitive functioning; the acquisition of age-appropriate skills; and reduced negative impacts of their disabilities (Hebbeler, Spiker, Bailey, Scarborough, Mallik, Simeonsson, et al., 2007; Bailey, Golden, Roberts & Ford, 2005). Families of children exiting Part C (child age 36 months) reported that EI services had "a lot of" impact on their children's development (75%) (Bailey et al., 2005; Markowitz, 2004).

The NEILS study also found a substantial number of the children participating in early intervention services, at risk of needing special education when they entered EI, no longer needed special services at 36 months (Hebbeler et al., 2007). Further, at kindergarten age, only 54% of the children who had been in early intervention were receiving special education services, and the EI children not in special education were found to be performing just as well as the general population of children in early reading and mathematics (Hebbeler, 2009).

Impact of Early Intervention on Family Outcomes. Results from the NEILS study provide evidence that families participating in EI services have high levels of confidence and self-report high levels of parenting skills. After receiving Part C services, the majority of families participating in early intervention reported that that they knew how to work with professionals and advocate for services (96%), knew how to help their children learn and develop (96%), and that EI professionals had helped them feel optimistic about their children's future (95%), (Bailey et al., 2005; Markowitz, 2004).

Other studies have found that early intervention can help families and other caregivers alter their style of interaction and more effectively recognize, respond to, and support young children with delays' attempts to communicate (Branson & Demchak, 2009; Fey et al., 2006; Yoder & Warren, 2002; Ward, 1999).

Intervention aimed at addressing children's special needs has also been demonstrated to have beneficial impact specifically on maternal depression. Researchers assessed maternal depression at three time points in intervention and control groups among mothers participating in a psycho-educational program aimed at teaching parents about learning and behavior problems in children (Bristol, Gallagher, & Holt, 1993). The intervention was offered to all mothers at the time of the child's autism diagnosis, and found that mothers who enrolled in the intervention had higher rates of depression (45% vs. 28%) than those who declined. The study also found mothers who participated had a reduction in depressive symptoms at the 18-month follow-up (to 10%), while rates of depression in mothers that did not enroll increased over time (to 42%).

In summary, outcomes for both children and families may be improved by early diagnosis, providing a mechanism through which the child and family may begin to receive early intervention services to address early language and social skill development and essential education, support, and resources for the family. Despite wide variations in service delivery systems for young children with disabilities across (and sometimes within) states, a developmental or medical evaluation and/or diagnosis is typically required as an initial step in accessing services. Children may receive diagnostic or evaluation services through medical or childcare professionals, referrals based on parent or family members' concerns, or involvement with existing public health or social welfare services. The next section reviews Part C, the primary service delivery system in the US for early intervention services for children age zero to three with delays or disabilities.

Program and Policy Context

Part C of IDEA. One key provider of early intervention services is the Infants and Toddlers with Disabilities Program, Part C of the Individuals with Disabilities Education Act (IDEA). The program provides early intervention (EI) services to children aged birth to three with developmental delays or a medical condition that are likely to lead to a developmental delay. In 2009, Part C served 348,604 children nationally (Data Accountability Center, 2010). Part C was created to enhance early development for infants and toddlers with disabilities, minimize potential developmental delay, and reduce educational costs to society by minimizing the need for special education services as children with disabilities reach school age (Individuals with Disabilities Education Act, 2004). The program is intended to work

in partnership with agencies and programs in health, education, human services, and developmental disabilities.

The Part C program emphasizes the vital role families play in optimizing their child's development, and aims to enhance family capacity to meet their child's special needs. This is operationalized through the requirement of an Individualized Family Service Plan (IFSP) jointly developed by families and providers, and a goal of service delivery in home and community settings typically available to all young children.

States vary in their processes for determining eligibility for Part C programs and services, using various combinations of developmental screening assessments, categorical eligibility (i.e. based on diagnosis of specific disorders or conditions), and clinical opinion. Among states and jurisdictions, variability among eligibility criteria for Part C programs varies in two main ways: definition of developmental delay and inclusion of risk factors (Shackelford, 2006). First is the issue of how the state defines developmental delay. States' cutoffs based on developmental assessments include use of percentage delays or percentile scores, scores falling within a specified standard deviation(s) from the mean, and performance relative to chronological age (e.g. six months delay) (Shackelford, 2006). The second main variable is whether states allow services to be delivered to children considered at-risk due to poverty, other environmental concerns, and/or involvement in social welfare systems, homelessness, or other risk factors.

A few states also serve infants and toddlers considered at risk for developmental delay due to environmental or biological factors (e.g. low birth weight,

poverty, or documented abuse or neglect). An additional factor in eligibility variability among states is the use of “informed clinical opinion”, or allowing professionals to deem a child eligible without the child meeting specified criteria, or as a substitute for using a standardized measure. For example, this approach might be used for a child not able to be accurately assessed with the usual instruments due to multiple impairments. In 2006, 37 of 56 states and jurisdictions (66%) with Part C programs allowed clinical opinion as an avenue for eligibility (Shackelford, 2006).

IDEA requires states to develop and implement a comprehensive system that incorporates efforts by states to locate and identify potentially eligible children (“child find”) as well as a system for providers and parents to refer children for eligibility determination (“referral”) (Early Intervention Program, 2002). States must incorporate public awareness campaigns or programs aimed at early identification, which might include print materials, public services announcements, toll-free telephone numbers, or other methods aimed at providing information to providers and parents. Operationalizing the IDEA requirements related to child find, referral systems, and eligibility processes and criteria into approaches and practices is necessarily complex in order to address the heterogeneity among state approaches (e.g. see Dunst and Trivette, 2004). However, all states have systems in place to address the various requirements for Part C.

Children may also be receiving early intervention services from sources outside of Part C, including Early Head Start, community based programs, or private intervention services (e.g. speech or behavioral therapies), among others. The current study has implications for processes through which children are identified,

referred, and potentially found eligible for early intervention services. Examining family variables that may be barriers to children entering services may potentially inform targeted child find and referral practices.

Unmet Needs. In 2009, 2.67% of the general population of children birth through 3 received early intervention through Part C (Data Accountability Center, 2010), while research indicates that 13% of children have developmental delays that would make them eligible (Rosenberg, Zhang, & Robinson, 2008). Additional studies found that among nine-month olds, only 9% of children who have delays that would make them eligible actually receive services, and at 24 months of age only 12% receive services (Feinberg, 2011). Among subgroups, black children are less likely to receive services than any other ethnic or racial group of children (Feinberg, 2011; Rosenberg et al, 2008).

Summary of Existing Literature

Research related to the presence of maternal depression among children with disabilities is fairly well documented, as are the potential sequelae of maternal depression on children. In addition, evidence is strong that early intervention can effectively ameliorate subsequent delays and disability, and potentially improve the developmental trajectories of children. The current study adds to the knowledge base by providing evidence of whether maternal depression is a significant factor in young children with delays accessing early intervention services.

The results of this study offer information that may be useful in improving early identification and pathways into care for subgroups of families with children with developmental delay. Understanding the role of maternal support and

depression is relevant to appropriately identifying children through child find efforts, and potentially tailoring interventions at the family level to address needs for parent support for young children. The goal is to ensure all children get needed referrals and evaluations in a timely manner, regardless of their family environment, thereby leading to earlier interventions for children with disabilities and their families. Further, assessment of family characteristics among families of children with disabilities might inform efforts specifically aimed at facilitating treatment for mental health issues among parents, which will have a direct positive effect on child development and parental health.

One aim of the currently proposed research is to provide specific information about how maternal depression may influence mothers' knowledge about whether their child has a developmental delay. This aim will be addressed by answering the first two research questions-

1. Among children with developmental delay at age two, what proportion of mothers report that their child has special needs? and
2. Among children with developmental delay at age two, does a mothers' report that the child has a special need vary according to the presence of maternal depression?

The second aim in the proposed study is to investigate the role of maternal depression in the proportion of children with documented developmental delay at age two that receive early intervention services, answering the question:

3. Among children with developmental delay at two years of age, is the presence of maternal depression associated with receipt of early intervention services?

For all analyses, the proposed study focuses on children who were not identified with delays as infants, thereby targeting the impact and role of maternal mental health to a specific group of children potentially eligible for early intervention. The sub-sample of children studied are those estimated to be eligible in their state, based on standardized assessments administered by the ECLS-B study, then compared to each child's state- specific early intervention eligibility criteria, derived from a national survey of state eligibility criteria. The methodology with which the current study will be undertaken follows in the next chapter.

CHAPTER 3: METHODS

The Early Childhood Longitudinal Study- Birth Cohort

The current investigation will utilize data collected as part of the Early Childhood Longitudinal Study-Birth cohort (ECLS-B), a study looking at children's health, development, care, and education from birth through kindergarten entry. The study was designed to provide policy makers, researchers, childcare providers, teachers, and parents with detailed and comprehensive information about children's early life experiences.

The main purpose guiding the design and content of the ECLS-B was to “assess children’s health status and their growth and development in domains that are critical for later school readiness and academic achievement” (preface; Moore, K., Manlove, J., Richter, K., Halle, T., Menestrel, S., Zaslow, M. et al., 1999). The study emerged in part to provide a mechanism to assess broader program and policy issues in the U.S. relevant to the development of young children and the characteristics of their families. The ECLS-B is conceptually based on an ecological model, considering the family, community, and childcare factors, in addition to individual child characteristics, influencing learning, and later academic success. The study also aims to fill gaps in research through its prospective longitudinal design, ability to analyze important subgroups in the U.S. (e.g. children from

American Indian and Latino families), and incorporation of multiple domains of assessment (e.g. disability, social and emotional well-being).

ECLS-B Population Frame and Sampling Design

The sampling design and specific procedures are outlined in the base year sampling report (Bethel, J., Green, J.L., Nord, C., Kalton, G., and West, J. 2005) and are summarized here. The ECLS-B selected a nationally representative probability sample based on the population frame of all children born in the United States between January and December of 2001. Cases were omitted for children born to mothers less than 15 years old or children who died or were adopted prior to the 9-month assessment.

The study uses a clustered list-frame design. Children were sampled from a set of primary sampling units (PSUs) and in some cases secondary sampling units (SSUs) using the National Center for Health Statistics (NCHS) vital statistics system. Primary sampling units were formed through combining adjacent counties using the Metropolitan Statistical Area (MSA) definitions for larger cities, and the NCHS health service areas (U.S. Department of Health and Human Services, National Center for Health Statistics 1991) for smaller cities and rural areas. To determine the size of the PSUs, the average number of births from 1994-1996 was used.

A total of thirty-six case strata were defined through cross- referencing race/ethnicity categories (American Indian, Chinese, Other Asian/Pacific Islander, Hispanic, Black non-Hispanic, and White non-Hispanic); birth weight (very low, moderately low, and normal); and plurality (twins versus other births) by the

stratification of region, median household income, proportion minority population, and metro versus non-metro area. When possible, PSUs were also stratified by high/low income and high/low minority status. Ninety-two core primary sampling units were constructed, with supplemental sampling units created in some of the larger PSUs.

The sample sizes needed for the ECLS-B race/ ethnicity domains (American Indian, Chinese, other Asian or Pacific Islander, Hispanic, Black, non-Hispanic, White, non-Hispanic) were mostly accomplished in the overall PSU design. However, due to the small proportion and geographical concentration of American Indian (AI) births, a supplemental PSU frame was developed and a supplemental AI sample selected. In total, over 14,000 children were sampled, yielding 10,688 children with a completed parent interview at the nine-month time point.

ECLS-B Data Collection Procedures

The children included in the ECLS-B were enrolled from birth through approximately nine months, and followed until their kindergarten year. Data were collected through direct child assessments and interviews with parents, teachers/ childcare providers and childcare directors. Children were considered enrolled in the study with the completion of the parent interview at around nine months. Parent interviews were considered complete if the interview was completed up to the child development section, with a minimum of 85 items complete (out of 295 items). After this enrollment period there were three additional periods of data collection: age two, preschool (age 3-5), and kindergarten. Due to different kindergarten criteria across states, there were two waves of kindergarten data collection.

Of the 10,688 cases with a completed parent interview at the nine-month time point, completed parent interviews were obtained for 9,835 children (92%) at the second time point (when children were approximately age two). Prior to the age two data collection, 84 children were lost from the study due to moving permanently out of the country, seven due to death, and the remainder due to various types of non-response. Completion of the parent interview was a necessary precursor to conducting the direct child assessments. The direct child assessment component was completed for 9,218 children. Response rates for the two-year old direct child assessment component are calculated and reported in several different ways. Among those with a completed parent interview, the un-weighted response rate was 93.7 percent (9,218 cases), and the weighted response rate was 94.2 percent. If considering all the eligible nine-month cases (i.e., regardless of the status of the completion of the age two parent interview) for which a direct child assessment was completed, the un-weighted response rate was 87.0 percent, and the weighted unit response rate 87.7 percent (Nord et al 2005).

Of the 9,218 cases for which a parent interview and a child-level data were available, the majority had both Bayley scales completed (9,099) and another 119 at one of the two Bayley scores completed (i.e. either the cognitive or the motor subscale) (Nord et al 2005).

The current study utilized data obtained from the direct child assessment and the parent interview at age two years. Data collection procedures for those two sections of the study are briefly described here. The psychometric properties of all the measures used are documented in the ECLS-B methodology report

(Andreassen, C., Fletcher, P., and West, J., 2005), and additional details on the measures used for the current study are discussed in detail in the “Measures Used” section.

All data collection waves included direct child assessments and parent interviews. The direct child assessments included measures of physical, cognitive, social/ emotional, and motor development and functioning. Direct child assessments and parent interviews took place primarily in the family’s home, conducted by field interviewers and supervisors from Westat. Data collectors also videotaped a brief parent-child interaction and completed several observational measures. For the parent interview, computer-assisted personal interviewing (CAPI) was the primary mode of data collection; self-administered questionnaires were also used for gathering information from the spouse/ partner of the parent respondent and for responses on sensitive items or scales.

Training of data collectors for the two-year old data collection wave consisted of both home study materials and in-person sessions for 16 lead trainers/ supervisors, and 135 field interviewers; the vast majority of both groups had also participated in the 9-month data collection. In-person training covered interview content, assessment practice, and study procedures and protocols, and ranged from 4.5 days (for returning interviewers) to 6.5 days (for interviewers new to the ECLS-B). Assessors were trained in using the CAPI through scripted practice scenarios, lecture, and practice recording responses. Interviewers were similarly trained in the procedures and content of the direct child assessments, through lectures and practice implementing the assessments with children.

Additional data were collected from teachers/caregivers and center directors for children in child care. These data are not used in the current study, but areas covered include caregiver-child relationship, family involvement, beliefs and attitudes about child development and learning, the center environment, and the caregiver's background, among others. Full details are available in the data collection manuals for the respective waves of data collection.

Procedures for the Current Study

The remainder of this chapter details the specific sample, measures, and analyses to be used for the current study examining the parental role in a child accessing early intervention services. The research questions are first reviewed:

1. Among children with developmental delay at age two, what proportion of mothers report that their child has special needs?
2. Among children with developmental delay at age two, does a mothers' report that the child has a special need vary according to the presence of maternal depression?
3. Among children with developmental delay at age two, is maternal depression associated with the receipt of early intervention services?

Sample

Because the focus of the research is to examine factors and pathways related to children ultimately receiving early intervention services, the goal was to create a sample of children that were demonstrating delay and who were eligible for early intervention services. To estimate each child's eligibility for early intervention, and therefore inclusion in the study sample, the following three data elements were used: 1) the child's degree of delay on a standardized measure administered by ECLS-B at age 2 years, 2) the state s/he lived in, and 3) the criteria for eligibility in each state. This approach addresses the fact that criteria for eligibility for early intervention vary by state, and a universal cutoff may not accurately presume eligibility for all children. This section further describes the methods used to create the sample of children with these three data components. The resulting sample- a group of children demonstrating delay and eligible for services in their state- will be used for analyses of all three research questions.

First, measurement of the child's performance on a standardized assessment, a common way to define developmental delay among young children, is described. In the ECLS-B study, one of the direct child assessments conducted at age two was the Bayley Short Form, Research Edition (BSF-R) (The Psychological Corporation, 2001). Children were administered two subscales (mental and motor) at this time point; the standardized T-scores provided in the ECLS-B data set from these two subscales were used. These scores are based on chronological age (obtained by subtracting the child's birth date from the date of the assessment), and norm-referenced by age group to have a mean of 50 and a standard deviation of ten. The

T-scores provide a measure of children's functioning compared to peers of the same age, providing an objective measure of development in cognitive and motor domains. Additional details about the BSF-R assessment and administration are provided below under the "Measures Used" section; additional information about analyses addressing variability in eligibility criteria follows. The standardized t-scores were used in combination with state-specific information to determine each child's inclusion in the sample for analyses.

State-specific Eligibility Sample

The next component of developing the sample of children to be used for analyses involved using data about the state the child lived in along with the eligibility criteria in that state. Although not all states were represented in the ECLS-B data, all states were first coded to determine eligibility criteria by state. The child's state of residence at the 2-year time point was used (i.e. the state in which the parent interview was conducted). The state of residence was missing at age two for 850 of the 10,700 cases in the data (8%); in these cases, the eligibility criteria for the state the child lived in at nine months were used. State-specific eligibility information was gathered from a 2006 survey of states, using data gathered from states' Part C applications and interviews with Part C coordinators in each state (Shakelford, 2006). Some states reported multiple criteria for eligibility, for example: two standard deviations below the mean or 30% delay in one developmental area; 1.5 standard deviations below the mean or 25% delay in two or more developmental areas; or clinical judgment of the multidisciplinary team. For states that reported multiple criteria, of which one was a standard deviation measure, the standard deviation

measure was used as the eligibility criteria for children who lived in that state.

Twenty-three states fell into this category. They ranged from one to two standard deviations below the mean, and may or may not have had secondary criteria (for example 1.5 SD below in one area or 1.0 SD below in two areas).

Eligibility criteria for the remaining states were re-coded to create a consistent approach for estimating early intervention eligibility based on standard deviation scores. The original criteria as reported by Shakelford (2006) and the re-coded standard deviation criteria are presented in Table 1. States that specified eligibility for early intervention in terms of a percent delay were classified partly using the definitions of other states that used multiple criteria. For example, seven of the nine states using 1.5 SD also specified that a 25% delay was the corresponding percentage delay. Of the remaining two, one did not specify another criterion, and one used a percentile score equivalent (the 7th percentile, which approximates 1.5 SD below the mean). Based on this majority, states that only reported using a 25% delay criterion were coded as eligible if they were 1.5 SD or below the mean. Six additional states fell into this grouping. Similarly, of the states using a two SD measure, those specifying a corresponding percentage delay ranged from 30-40% delay; no states used a percentage only within this range. The next cluster was a grouping of states using a 50% delay in one or more areas (or in combination with a 25% delay in two or more areas). These were re-classified as using a cutoff of two SD in one area or 1.5 in two areas, a more restrictive cutoff level.

Another group of states (eight states) reported a qualitative measure such as “a significant delay/difference between expected and current level of functioning”,

“outside the range of ‘normal’ or ‘typical’ for same age peer”, “substantial delay or atypical development in one or more areas, supported by observation, measurement or judgment”, or “informed clinical opinion of a multidisciplinary team.” Children from these states were included as EI eligible if they met the criterion of scoring 1.5 SD or below the mean in one developmental area. Although “clinical judgment” cannot be quantitatively defined in this scenario, the 1.5 SD criteria corresponds to approximately the lowest 7% of children in a given domain. The assumption is that professionals skilled in assessment and determining. The original coding and re-coding, along with number of states in each grouping, are in Table 1. Fifty U.S. states and the District of Columbia were coded (n=51).

If the state specified scoring relative to a cut point for one domain, a child could be included based on scores on either of the two subscales. If the state allowed use of a higher cut point on two subscales, those criteria were used for children in those states. Using these criteria, children could be included in the final sample based on their T-scores on the Bailey motor and mental subscales, along with their state of residence and the eligibility criteria for that state. Some additional criteria were also used, described next.

Table 1: Early Intervention Eligibility Coding for All States

Original Eligibility Codes	Number of states	Re-grouping by SD only	Number of states	T-score
1.0 SD in one area	1	1.0 SD in one area	1	40
1.3 SD in one area	1	1.3 SD in one area	1	37
1.75 SD in one area	1	1.75 SD in one area	1	33
1.5 SD in one area; 1.0 in two areas	1	1.5 SD in one area; 1.0 in two areas	1	35 (40 in two)
1.5 SD in one area	8	1.5 SD in one area	22	35
25% delay in one area	6			
Significant delay/difference	6			
Clinical opinion only	2			
2 SD in one or more areas	1	2 SD in one area	7	30
50% delay in one area	4			
Others (30-33% delay in one area)	2			
2 SDs in one area; 1.5 SDs in two areas	11	2 SD in one; 1.5 in two	18	30 (35 in two)
50% delay in one area; 25% in two or more	4			
Others (33-40% delay in one area or 25% delays in two areas)	3			
Total	51	Total	51	

Other Criteria for Inclusion in Sample

The current study is focused on the investigation of children who are not already identified based on early risk factors. Among the group of children who were estimated to be eligible in their state at age two (using their T-scores, state of residence, and their states' eligibility criteria), some children would likely have already been identified at earlier ages and already be in early intervention services.

Therefore, we excluded children previously reported to have delays or conditions at birth that made them eligible at age 9 months. Children were excluded whose parents reported the following conditions prior to age two: heart defect, blindness, difficulty seeing, difficulty hearing, cleft lip/palate, failure to thrive, problem with mobility, problem with using hands, down syndrome, spina bifida, turners syndrome, or other special need. Some, but not all of the conditions are associated with developmental delay. However, all were excluded in creation of the sample as they suggest early involvement with health care professionals and systems through which their health and development was potentially monitored more closely.

Another group of children who are often more closely followed by health professionals as infants and toddlers are those born pre-term or at low birth weight. We excluded from the sample children born less than 2500 grams (or 5.5 pounds) and children born prior to 37 weeks gestation, as reported on the child's birth certificate.

Due to the very small number of non-biological mother respondents (e.g. stepmothers, foster mothers), the sample was further limited to biological mothers as

the respondent at age two. Finally, due to the relationship of maternal factors and child outcomes, for cases where twins were both in the developmentally delayed sample, one of the cases was omitted so that there was only one parent-child pair in the sample. The final sample consisted of approximately 600 children with developmental delay. Consistent with ECLS-B reporting requirements, both unweighted and weighted sample sizes are required to be rounded to the nearest increment of 50; subgroups or cells smaller than 50 are not allowed to be reported, thus 600 reflects the rounded sample size.

To summarize, children were included in the final sample if it was determined that they should have met eligibility criteria in their state based on their degree of delay, they were not previously identified with any disability at nine months, and they were full-term (37 weeks or greater) and of normal birth weight. This group of children comprised the sample for all analyses presented here. The following section describes in more detail the measures used.

Measures Used

Child's developmental status. As outlined above, the sample is partly defined by children's developmental status at age two as measured by an adaptation of the Bayley Scales of Infant Development II (BSID-II) (The Psychological Corporation, 1993). The administration of the full BSID-II was determined to be too burdensome considering the range of other assessments at each home visit. Therefore, the Bayley Short Form, Research edition (BSF-R) was developed as a shortened version of the BSID-II. The core set for the two-year BSF-R mental scale has 19

items drawing from content areas of memory, means-end behavior, exploratory competence, and communication. The BSF-R motor scale includes 17 items including fine motor (e.g. reaching and grasping, manipulating objects, using a pencil) and gross motor development (sitting, standing, walking, and balance). The mental and motor scale items selected were organized as a core set to be administered to all children. Performance on this core set determines whether any supplementary sets of items are administered. Supplementary sets of questions include those for children whose scores were low and high on the core set (therefore administered sets of easier or harder questions, respectively).

The BSF-R was designed to correspond to the 23–25-month item set of the BSID-II. The core items on the mental scale range from 17 months to 37 months, the basal items go down to 12 months, and ceiling items extend up to 42 months. For the motor scale, core items range from 13 to 37 months, with the basal items reaching down to 11 months, and ceiling items to 42 months. The majority of children (90%) were assessed within the range of 23–25 months, with 1.6% assessed before they were 23 months old and 8.4 percent assessed at 26 months or older. Trained assessors administered these items directly with the children in the families' homes or childcare centers.

Maternal Depression. At age two, information about the presence of depressive disorders was gathered from the respondent using the depression scale of the Composite International Diagnostic Interview Short Form (CIDI–SF) (Walters, Kessler, Nelson, and Mroczek 2002). The CIDI–SF was originally developed for use in the National Health Interview Survey (NHIS), with items selected from the larger

CIDI (WHO 1990), an instrument widely used in large-scale, cross-cultural epidemiological studies of the prevalence of mental disorders internationally. Unlike depression screening instruments, the CIDI-SF is a diagnostic tool, allowing the evaluation of specific symptoms associated with depression, and is designed to diagnose depression, corresponding to the diagnostic criteria in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) (American Psychiatric Association 1994). The original CIDI-SF script inquired about the past 12 months, and was adapted for the ECLS-B study to inquire about the time since the previous interview (i.e. since the 9-month data time point, or approximately in the previous 15 months).

The recommended scoring criteria for the CIDI was followed (see Nelson, Kessler, & Mroczek, 2001). The CIDI-SF scale uses stem questions ascertaining presence and persistence of mood changes over a period of at least two weeks. These two stem areas are having at least two weeks of dysphoric mood (anxiety, depression, or unease) or to endorse all questions about anhedonia (lack of pleasure or capacity to experience pleasure). If the stem questions are not endorsed, the respondent skips out of the rest of the scale. If stem questions are endorsed, subsequent questions gather information on specific symptomology of different aspects of depression, such as losing interest, trouble with sleep or concentration, weight changes, feeling tired or down, and thoughts about death. The symptoms also must meet criteria of frequency of at least most of the day, almost every day. The CIDI-SF yields a score of the probability of the individual meeting full diagnostic criteria based on their depression score; these probabilities range from

0.0 through 1.0. In addition, recommended cutoffs are provided for the purposes of dichotomizing whether the individual will meet full diagnostic criteria based on the summary score (a range from zero to seven). The recommended cut-point score is three and above; this was used to score the CIDI-SF and categorize mothers as “depressed” or “not depressed.” The corresponding probabilities of meeting case criteria with scores from three to seven range from 0.6 to 0.9 (Nelson, Kessler, & Mroczek, 2001).

Demographic Covariates. Demographic information includes mother’s age, race/ ethnicity of the child, number of well-child check-ups, maternal support (presence of a partner in household), and socioeconomic status (SES). Other variables were used to provide additional detail about the sample, but are not entered as covariates in the regression model, such as the overall health of the child and mother, and place of regular medical care. The measure of SES was based on multiple demographic components, and therefore will be more fully explained here.

The SES variable is a composite measure of social standing, computed at the household level using the following components: father/male guardian’s occupation and education, mother/female guardian’s occupation and education, and household income. The SES variable reflects the socioeconomic status of the household at the second data collection point (age two). The SES composite variable used for the current study groups families by quintiles based on their combined SES score. For descriptive and regression analyses, the SES quintiles are grouped according to: 1) the lower two quintiles and 2) the upper three quintiles.

Parent education and occupation data were collected in the CAPI parent interview and the resident father questionnaire. Income information was also collected in the 2-year parent CAPI instrument. All participants were asked broad and detailed income questions, first classifying households as \$25,000 and less, or greater than \$25,000 per year. Detailed ranges followed, and households near Census poverty thresholds were additionally asked to report “exact” income (to the nearest \$1,000). For households not asked to report exact income, the midpoint of the detailed income range was used in computation of the SES composite variable.

The ECLS-B study used the *Standard Occupational Classification Manual* (Executive Office of the President, Office of Management and Budget, 2000) to code occupations, which were then collapsed into 24 categories, including one for unemployed, retired, or disabled workers. Occupations were recoded to reflect the average of the 1989 General Social Survey (GSS) prestige score, computed as the average of the corresponding prestige scores for 2000 Census occupational categories covered by the ECLS-B occupations.

Missing data percentages were small for mother and father occupation and education (from 0.15% missing for maternal occupation to 1.21% missing for father’s education), and somewhat higher for missing income data (3.4%). Missing SES composite variables were imputed using hot deck imputation methods, defining imputation cells by respondent characteristics and type of household. The order of factors used for imputation procedures for income, occupation, and education are fully described in the ECLS-B 9-month to 2-year data User’s Guide (Nord, et al.,

2006). Together these variables were used to create an SES score, and subsequent quintile grouping, for all respondents.

Outcome Variables

This section describes the outcome variables used for the three research questions. All outcome variables were based on various components of the parent interview used in the ECLS-B, conducted when children were age two.

Parent awareness of special needs. When the child was age two, all parents were asked whether their child had any special needs, whether or not an earlier delay or disability was reported. Because the sample for this study excluded children whose parents had reported an earlier delay or condition (up to age nine months), this question will differentiate parents based on their identification of their child as having a special need at age two. The question specifically asks “Has a doctor ever told you that (child) has the following conditions? Does he/she have...[blindness; deafness or difficulty hearing (beyond temporary losses due to sickness or ear infections); problems with mobility, delay in walking, delay in talking, other developmental delay, and/or mental retardation]?” In addition to those listed, parents were also asked about some conditions *not* associated with developmental delay, including crossed or wandering eye, correctable vision difficulties (e.g. near- or far-sightedness), heart defect, epilepsy/ seizures, lactose intolerance, and food allergies. These conditions were excluded. The conditions noted by mothers were tallied and a dichotomous outcome variable created: either no condition was reported (therefore coded “no”, parent is not aware of any disability or delay), or one

or more conditions were reported (coded “yes”, parent is aware of a disability or delay).

Child receipt of services. When the child was age two, all parents were asked whether their child was currently receiving any services to help with any special need(s) the child may have, and subsequently asked about what services the child was receiving. Specifically, parents were asked “There are services available to families with children who may have special needs. For example, parents may seek language or physical therapy for their children. They may place their children in special classes with other children who have similar needs, or they may seek support or training for themselves. Does (child) or your family receive any services to help with special needs that child may have?” The specific services asked about included: speech or language therapy, occupational therapy, physical therapy, vision services, hearing services, social work services, psychological services, home visits, parent support or training, and/or special classes with other children with special needs. The services received for each child were tallied and a dichotomous outcome variable created: either no services were reported (therefore coded “no”, child did not receive services), or one or more services were reported (coded “yes”, child did receive services).

If the mother had identified the child as receiving services, she was also asked about the type of provider of the services (local school district; state or local health or social service agency; a doctor, clinic, or other health care provider; or any other source) as well as the average number of hours of services per month the child received across all services.

Data Analysis

Approximately 600 children met criteria for inclusion for analyses. All analyses were done with PASW Statistics, version 19 (IBM SPSS, Inc., 2010), utilizing the application of data weights to account for the complex sampling design of the ECLS-B and to generate population estimates. The weighting variable used was “W2CO”, recommended for analyses using direct child data in combination with parent level data. The weight adjusts for non-coverage of the target population, disproportionate sampling, and survey non-response (Nord, Edwards, Andreassen, Green, & Wallner-Allen, 2006). The weighting variable is cumulative, adjusting for parent and child variables at both the nine-month and age two data collection.

For research question one, a weighted percentage has been reported on the overall proportion of mothers reporting that their child has special needs. For research question two, logistic regression analysis was used to test differences in proportions among mothers who report their child has a special need according to their depression status. The regression (beta) coefficients were used to compute crude and adjusted odds ratios (ORs) with 95% confidence intervals obtained from the logistic regression models. Variables that are included in the adjusted model include the following: race/ethnicity, SES quintiles, partner status (whether or not mother is living with a partner), the mean of the child’s mental and motor t-scores, maternal age, and number of well-child visits.

For the third research question, analyses are similar to the preceding research question: logistic regression analysis were used to test differences in

proportions among mothers who report their child is in early intervention services according to their depression status. Adjusted odds ratios (ORs) were computed by using the regression (beta) coefficients and 95% confidence intervals obtained from the logistic regression models. The adjusted model includes race/ethnicity, SES quintiles, partnered status (whether or not mother is living with a partner), the mean of the child's mental and motor t-scores, maternal age, and number of well-child visits.

Protection of Human Subjects in Research/ Institutional Review Board

The University of North Carolina at Chapel Hill Institutional Review Board (IRB) reviewed this study and found it to be exempt from full review based on the study utilizing secondary data, with little to no risk for identification of participants. The IRB review study number is 12-0585.

CHAPTER 4: RESULTS

This chapter describes the characteristics of the sample, including demographic characteristics of the family and child, and then presents results according to the primary research questions.

Demographics and description of the sample

Among the 10,700 children included in the data, 600 children met the criteria for developmental delay defined by their state and were determined to be eligible for early intervention services. Specifically, they were not previously identified with a condition or disability, were full term and of normal birth weight, and had a unique biological mother respondent, as defined in the methods section. All analyses were conducted with this sample.

Descriptive characteristics of the households, mothers, and children in the sample are shown in Tables 2, 3, and 4, which display comparisons of the study sample with the full set of ECLS-B data. Almost half of the children in the sample (49.1%) reside in families in the bottom two SES quintiles, and a large majority of children reside in two-parent households with both biological parents.

Compared to data from the overall ECLS-B population, the sample has a higher percentage of male children (64% in the sample vs. 51% in the ECLS-B population), a higher percentage of Hispanic children (39% in sample vs. 25% in

population), and more children in households in the lower two SES quintiles (49% of sample vs. 40% of the ECLS-B population).

Mothers of the children in the sample were more likely to speak languages other than English (30%) compared to mothers in the ECLS-B population (18%). Mothers in the sample were also more likely to be born in a US territory or other country (32%) than in the ECLS-B population (21%). While mothers' countries of origin were not specifically analyzed, the predominant other language spoken was Spanish. Mothers in the sample were more likely to have education below a high-school diploma (35%) compared to the larger population (27%). Sample children were slightly more likely to be living in single-mother headed households (26% vs. 20%).

Table 2: Child Demographic Characteristics

Child characteristics	Sample (weighted n=300,200)		Population (weighted n=3,965,700)	
	Weighted N*	Percent	Weighted N*	Percent
Child gender				
<i>male</i>	190,600	63.5%	2,031,800	51.2%
<i>female</i>	109,550	36.5%	1,933,900	48.8%
Child's Race/ Ethnicity				
<i>White/ non-Hispanic</i>	121,300	40.4%	2,118,300	53.6%
<i>Hispanic, any race</i>	117,050	39.0%	1,000,350	25.3%
<i>Black or African American</i>	33,700	11.2%	541,400	13.7%
<i>More than one race, non-Hispanic</i>	14,300	4.8%	159,600	4.0%
<i>Asian</i>	11,150	3.7%	107,200	2.7%
<i>American Indian/ Alaska Native</i>	2,100	0.7%	20,450	0.5%
<i>Pacific Islander/ Native Hawaiian</i>	550	0.2%	8,300	0.2%
Birth weight				
<i>Normal weight (>2500g or ~5.5 pounds)</i>	300,200	100%	3,666,750	92.5%
<i>Birth weight below 2500 g</i>	n/a	n/a	297,200	7.5%
Prematurity				
<i>Full term (40 weeks or more)</i>	280,200	93.3%	3,457,300	87.2%
<i>One week preterm (39 weeks)</i>	8,500	2.8%	167,050	4.2%
<i>Two weeks preterm (38 weeks)</i>	6,050	2.0%	103,550	2.6%
<i>Three weeks preterm (37 weeks)</i>	700	0.2%	63,900	1.6%
<i>Not ascertained</i>	4,750	1.6%	48,300	1.2%
<i>More than three weeks preterm</i>	n/a	n/a	125,600	3.2%
Multiple birth status				
<i>Singleton birth</i>	295,550	98.5%	3,832,450	96.8%
<i>Twin in household</i>	4,550	1.5%	119,050	3.0%
<i>higher order multiples</i>	n/a	n/a	7,100	0.2%
Child's overall health				
<i>excellent</i>	162,800	54.2%	2,441,350	61.6%
<i>very good</i>	87,500	29.1%	1,052,250	26.5%
<i>good</i>	43,400	14.5%	386,950	9.8%
<i>fair/poor</i>	6,450	2.2%	84,400	2.1%
Place for well-baby check ups				
<i>Doctor's office or HMO</i>	200,400	66.8%	2,954,500	74.5%
<i>Health center or clinic</i>	85,250	28.4%	894,200	22.6%
<i>Hospital outpatient or Emergency room</i>	4,500	1.5%	47,400	1.2%
<i>Not applicable</i>	10,050	3.4%	64,250	1.6%
<i>Other place or no regular place</i>	0	0%	4,500	0.1%
Number of well-baby checks				
	mean	range	mean	range
	2.9 visits	0-20	2.9 visits	0-20
Developmental Status				
	mean	range	mean	range
<i>motor t-score</i>	33.98	3-67	50.0	3-97
<i>cognitive t-score</i>	36.55	15-73	50.0	15-88

* Rounded to nearest 50 due to ECLS-B reporting standards

Table 3: Maternal Demographic Characteristics

Maternal characteristics	Sample (weighted n=300,200)		Population (weighted n=3,965,700)	
	Weighted N*	Percent	Weighted N*	Percent
Maternal education (highest completed)				
<i>Some high school or below</i>	106,050	35.3%	1,070,250	27.1%
<i>High school diploma or equivalent</i>	63,150	21.0%	851,800	21.6%
<i>Some college or vocational/ technical program</i>	76,050	25.3%	1,049,900	26.6%
<i>Bachelor's degree or higher</i>	54,950	18.2%	976,850	24.6%
Mother's age				
<i>Ages 17-24</i>	88,550	29.5%	101,2400	25.6%
<i>Ages 25-34</i>	149,400	49.8%	203,3200	51.5%
<i>Age 35 and older</i>	62,250	20.7%	904,900	22.9%
	mean	range	mean	range
<i>Mothers age overall</i>	29.0 years	17-47	29.5 years	17-70
Respondent marital status				
<i>Married</i>	186,500	62.1%	2,687,650	67.8%
<i>Separated/ divorced/ widowed/ never married</i>	113,700	37.9%	1,277,000	32.2%
Respondent's country of birth				
<i>United States</i>	203,500	67.8%	3,146,800	79.4%
<i>US Territories or another country</i>	96,650	32.2%	818,200	20.6%
Respondent's primary language				
<i>English</i>	209,300	69.8%	3,244,000	81.8%
<i>Another language</i>	90,900	30.2%	721,000	18.2%
Respondent's overall health				
<i>excellent</i>	87,000	29.0%	1,331,400	33.6%
<i>very good</i>	98,650	32.9%	1,380,400	34.8%
<i>good</i>	87,600	29.2%	930,300	23.5%
<i>fair/poor</i>	26,950	9.0%	322,250	8.2%

* Rounded to nearest 50 due to ECLS-B reporting standards

Table 4: Household Characteristics

Household Characteristics	Sample (weighted n=300,200)		Population (weighted n=3,965,700)	
	Weighted N*	Percent	Weighted N*	Percent
Parents residing in household				
<i>Biological mother and any father type</i>	222,450	74.1%	3,115,000	78.6%
<i>Biological mother only</i>	77,750	25.9%	793,250	20.0%
<i>Other parent combinations (e.g. father only, adoptive parents, guardian(s))</i>	n/a	n/a	51,900	1.4%
Socioeconomic scale (quintiles)				
<i>Lower two quintiles</i>	147,600	49.1%	1,584,200	39.9%
<i>Upper three quintiles</i>	152,550	50.8%	2,381,500	60.1%
Anyone in household with special need? (other than focal child)				
Yes	35,900	12.0%	342,450	8.6%
No	264,250	88.0%	3,621,750	91.4%

* Rounded to nearest 50 due to ECLS-B reporting standards

Proportion of mothers reporting children's special needs

The first research question addressed in this study was, "Among children with developmental delay at age two, what proportion of mothers report that their child has special needs?" Results show that 11.3% of mothers (N=33,700) reported their child had a special need. As described in the "outcome variables" section, this percentage includes mothers that reported a physician had told them that their child had one of the following conditions: blindness; deafness or difficulty hearing (beyond temporary losses due to sickness or ear infections); problems with mobility, delay in walking, delay in talking, other developmental delay, and/or mental retardation. Excluded conditions not associated with delay (e.g. epilepsy/ seizures, food allergies, heart defect) were not included in the analyses and not included in the 11.3% identification rate reported.

Among mothers reporting conditions, the majority (66.3%) reported one condition or impairment, with another 22.8% reporting two conditions. Of the remaining mothers, 5.7% reported three conditions, and 5.2% reported four conditions. The mean was 1.5 reported conditions per child. Table 5 presents the weighted frequencies for the types of disabilities reported by mothers.

Table 5: Types of Children's Disabilities Identified by Mothers in the Sample (weighted n=300,200)

Disability or condition reported	Weighted N	Percent of sample*
Delay in talking	32,750	10.9%
Delay in walking	9,800	3.3%
Difficulty hearing	7,950	2.6%
Other developmental delay	5,900	2.0%
Mobility problems	2,650	0.9%
Blindness	2,250	0.8%
Mental retardation	1,600	0.5%

* Mothers could report more than one disability, so percentages do not add up to the 11.3% overall rate reported

Maternal Depression and Identification of Special Needs

The second research question was “Among children with developmental delay at age two, does a mothers’ report that the child has a special need vary according to the presence of maternal depression?” The distribution of maternal depression among subgroups is summarized in Table 6.

Overall, 6.4% of mothers in the sample (n=50, weighted n=19,150) met the criteria for clinical depression. This rate varied by both race/ethnicity and SES subgroups. The rate was higher among mothers of children who were white/ non-Hispanic (9.3% met depression criteria) compared to Hispanic (4.3% met depression criteria) and other race/ethnicity groups (4.6% met criteria). The percentage of mothers meeting criteria for depression was somewhat lower among the higher SES grouping (the upper three quintiles) (5.3% met depression criteria) compared to the lower SES group (the bottom two SES quintiles) (7.6%).

To answer this research question, logistic regression analysis was used to investigate the association between the mother’s depression status and her identification of the child’s disability (see Table 6). Among mothers of the 600 children in the sample who were eligible in their state, 10.9% of mothers without depression reported that their child had a special need, compared to 17.2% of mothers with depression. Results of the adjusted analysis show that among children with developmental delay who are eligible for services in their state, mothers with depression are significantly more likely than mothers without depression to report

that their child has a disability (adjusted OR=1.75 [95% confidence interval CI 1.65-1.83]).

The odds ratio was adjusted for race/ethnicity groups, SES quintiles, partnered status (whether or not mother is living with a partner), the mean of the child's mental and motor t-scores, maternal age, and the number of well-child visits.

Table 6: Relationship between Maternal Depression and Identification of Child Disability

Depression status	Percent of Sample Identifying Disability	Crude OR (95%CI)	Adjusted OR* (95% CI)
Non-depressed	10.9%	1.0 (reference)	1.0 (reference)
Depressed	17.2%	1.83 (1.76-1.91)	1.75 (1.65-1.83)

Maternal Depression and Child's Receipt of Services

The last research question was "Among mothers of children with developmental delay at age two, is receipt of early intervention services associated with the presence of maternal depression?" Descriptive information on the characteristics of services received by children in the sample is summarized in Table 7.

Overall, among the sample of children in the study who were eligible for early intervention in their state, 5.9% (n=17,700) of children were receiving services. The majority of parents (86%) reported receipt of more than one service; on average parents reported that their child received about three different intervention services (2.9). Table 7 shows the types of services parents reported, the service systems through which the children are getting services, and the number of hours of services

they are receiving. Speech-language services were the most frequently reported (79%) followed by home visits (59%). The category “home visits” likely reflects the modality of services, rather than a specific service in and of itself, and likely overlaps with other services reported. For example, children may be receiving speech therapy in the home and therefore endorse both “speech-language services” and “home visits”, while this may in practice reflect essentially one service. Part C early intervention services are required to be provided in the child’s natural environments, the primary one being the child’s home. Other services reported in higher numbers were physical therapy (32%) and/or occupational therapy (30%). Parent training and support services to parents are also included in the list (27% reported). The mean number of hours reported among this subgroup was about 14 hours per month.

Table 7: Type of Services Received among 17,700 Children Receiving Services

Type of services received*	Weighted n	Percent receiving service
Speech or language therapy	14,000	79.1%
Home visits	10,400	58.9%
Physical therapy	5,600	31.7%
Occupational therapy	5,350	30.2%
Parent support or training	4,850	27.4%
Hearing services	4,600	26.0%
Special classes with other children with special needs	4,000	22.6%
Social work services	3,300	18.7%
Vision services	2,550	14.3%
Psychological services	1,950	11.0%
Hours of Services	mean	range
Number of hours of services (per month)	13.8	1-51
Services Provider*	Weighted n	Percent
State or local health or social service agency	8,400	47.4%
A doctor, clinic, or other health care provider	7,700	43.5%
Local school district	4,200	23.7%
Some other source	600	3.5%

* Mothers could report more than one service received and more than one provider of services, so percentages do not add up to 100% within the subgroup

To answer the third and final research question, logistic regression analysis was used to examine the association between the mother's depression status and the child's receipt of early intervention services (see Table 8). Results show that among children with developmental delay who are eligible for services in their state, maternal depression is associated with a slightly increased probability of acquiring early intervention services (adjusted OR=1.14 [95% confidence interval CI 1.07-1.20]). Comparison of the child's receipt of early intervention services by the mother's depression status showed that 5.7% of mothers without depression reported their child had received services, compared to 8.0% of mothers with depression.

The odds ratio was adjusted for race/ethnicity groups, SES quintiles, partnered status (whether or not mother is living with a partner), the mean of the child's mental and motor t-scores, maternal age, and number of well-child visits.

The adjusted odds ratio approached one with all covariates included. The inclusion of race/ethnicity in the stepwise model attenuated the odds ratio. There were differential rates of children receiving services among race/ethnicity subgroups: 10.0% of Caucasian children were in services, 3.4% of Hispanic children, and 2.4% of other minority children (including black, American Indian/Alaskan Native, and Asian children).

Table 8: Relationship between Maternal Depression and Child Receipt of Services

Depression status	Crude OR (95%CI)	Adjusted OR (95% CI)
Non-depressed mothers	1.0 (reference)	1.0 (reference)
Depressed mothers	1.48 (1.40-1.56)	1.14 (1.07-1.20)

Additional Analyses

To explore the differential rates of mothers with depression identifying their child's disabilities and receiving early intervention services, additional analyses were completed. These analyses examined several components of help-seeking behaviors among mothers, including seeking help for their own depression and for their child's delays, as potential pathways through which mothers are ultimately accessing services for their child. Analyses first looked at the degree of impairment related to the mothers' depression. Additional variables were then considered, including whether the mothers sought professional help related to their depression and patterns of help-seeking for their child via well-child pediatric visits. These questions were asked within the parent interview when the child was age two.

To look at the degree of impairment associated with depressive symptoms, an analysis was made of maternal responses to the question "How much did sad or blue feelings interfere with your life or activities?" Results show that among women that met criteria for depression, the majority (59%) reported that the symptoms impacted them "a lot", with only a small minority (7%) reporting that symptoms impacted them "not at all" (see Table 9). Among mothers that did not meet criteria for depression, 6.5% reported depression symptoms that interfered with activities "some or a little" or "a lot", while the majority reported no impact or did not report any

depression symptoms (93.5%). It is clear that mothers with depression are reporting impairments in everyday functioning that would be consistent with episodes of clinical depression.

Another series of questions looked at mothers' patterns of help seeking related to their mental health concerns. Mothers were asked to respond to these questions considering the previous 12 months. Among women with depression in the sample, half told a doctor about their concerns, and half reported having talked with a psychiatrist, therapist, or doctor about an emotional or psychological problem. About 40% reported telling their concerns about feeling sad or blue to another professional, including a social worker, psychologist, nurse, clergy person, or other professional. These results showing large percentages of women seeking help for their emotional symptoms is promising; however, it is still not clear how their interactions with health, mental health, and other professionals may be playing a part in mothers' accessing services for their children.

One additional variable of interest was the degree to which mothers accessing pediatric services for their child did so at different rates based on their depression status. This may partly explain their higher rates of identification of disabilities, as a primary function of well-child visits is to assess young children's development through formal or informal screening practices. In addition, more frequent pediatric visits might indicate the child is under surveillance by his/her physician for developmental concerns, or indicate elevated parental concern. Descriptive analyses did show that mothers with depression reported taking their children to more well-child visits, reporting a mean of 3.5 visits since the previous

ECLS interview (at nine months), compared to 2.8 visits among mothers without depression. A t-test comparing these means found the difference to be statistically significant ($p < .01$). Twenty percent of the mothers with depression reported that they went to five or more well child visits in the time since the previous interview (approximately 15 months), compared to 7.7% of mothers without depression. These supplemental analyses are re-visited again in the following chapter.

Table 9: Mental Health Symptoms among Mothers with and without Depression.

Impact of Depression Symptoms	With Depression (n=19,150)	Without Depression (n=281,000)	Total (n=300,200)
How much did sad/ blue feelings interfere with your life or activities?			
<i>A lot</i>	59.3%	3.2%	6.7%
<i>Some or a little</i>	34.0%	3.3%	5.3%
<i>Not at all</i>	6.7%	8.3%	0.5%
<i>Not applicable (no symptoms reported)</i>	n/a	85.2%	87.5%
Total	100%	100%	100%
Help-seeking for Depression Symptoms	With Depression (n=19,150)	Without Depression (n=281,000)	Total (n=300,200)
Ever told a doctor about feeling sad or blue	51.1%	3.7%	6.7%
Ever told another professional about feeling sad or blue (nurse, clergy, etc)	39.8%	1.9%	4.3%
Ever took medication for feeling sad or blue	47.9%	1.5%	4.5%
Talked with a psychiatrist or counselor for an emotional or psychological problem	50.2%	9.7%	12.3%

Table 10: Frequency of Accessing Pediatric Service use by Mothers of Children with Disabilities stratified by Presence of Maternal Depression.

Number of well-baby visits	With Depression (n=19,150)	Without Depression (n=281,000)	Total (n=300,200)
Well-baby visits (groupings)			
<i>1-2 visits</i>	33.3%	45.1%	44.4%
<i>3-4 visits</i>	46.6%	47.1%	47.1%
<i>5 or more visits</i>	20.1%	7.7%	8.5%
total	100%	100%	100%
Well-baby visits (mean)	3.5 visits	2.8 visits	2.9 visits

CHAPTER 5: DISCUSSION

This chapter summarizes the findings from the three research questions and additional analyses, discussing results in more detail and providing comparisons to other research findings. This chapter also discusses several important limitations to the current study, and concludes with a section highlighting policy and practice implications of the findings and directions for future research.

Summary of Results

This study examined maternal characteristics related to the likelihood of young children with developmental delays accessing early intervention services. The investigation centered on maternal perceptions of special needs and associations between maternal depression and children's receipt of services. Among the sample of children who were determined to be eligible for early intervention based on their state of residence and their developmental scores, the study found that overall, 11.3% of children were reported by their mothers to have a special need or condition. The analyses further showed mothers who met diagnostic criteria for clinical depression (6.5% of the sample) were almost two times more likely to report their child's needs than mothers without depression ($OR=1.75$). Mothers with depression were also found to be more likely to report that their child was receiving services, although this was a smaller association ($OR=1.15$). Findings showed that overall only 6.9% of children in the sample were receiving services.

The first research question found that 11.3% of eligible children were identified by a physician or health professional as having a delay, according to maternal report. This is a remarkably low percentage considering the overall developmental profile among the sample. Among the sample, the mean t-score for motor development was 34, corresponding to about 1.6 standard deviations below the mean, and to a percentile rank of about 5.5. The mean t-score for cognitive development was slightly higher at 36.6, corresponding to 1.4 standard deviations below the mean, and to a percentile rank of 8.0. Considering these descriptive statistics, it is surprising that more children are not being identified as having delays.

It is possible that more parents than the reported number are aware that their child's motor or cognitive functioning might be delayed, but either do not consider this to be a special need, are not concerned enough to pursue evaluation and diagnosis, or chose not to report it in the ECLS-B study questionnaire. In addition, the wording of the specific question used to assess parent report asked whether the parent had been told by a physician that the child had one of the conditions. It is possible that another subset of parents may have had concerns themselves, but had not been told by a professional that their child had any delays. Also, both parents and professionals may hesitate to assign a label to a child as young as age two; it is common for parents and health care providers to adopt a "wait and see" approach, particularly due to the wide age ranges considered to be within normal limits for accomplishing many child development milestones. Finally, parents' propensity to identify their child as delayed might be impacted by emotional factors related to accepting that their child might have a developmental delay or other special need, or

cultural or religious factors related to seeking out professional information about their concerns.

The next two research questions assessed relationships among maternal depression and two primary outcome variables: parent identification of special needs and children's receipt of services. The percentage of mothers in the current study found to meet criteria for depression was 6.5% using a measure (the CIDI-SF) designed to estimate diagnosable depression disorders according to the DSM-IV criteria (American Psychiatric Association 1994). The rate found in the current sample was comparable to the lower end of maternal depression rates reported in a meta-analysis of maternal depression studies, which reported results ranging from 6.9% to 12.9% (Gavin et al, 2005). The rate found was also comparable (6.5%) to the percentage of mothers reporting "severe" depressive symptomology using the CES-D scale (Radloff, 1977) administered at the nine-month time point in the ECLS-B study (Huang, et al, 2007). While research findings related to differential rates of depression among subgroups have been mixed, results from this study did find depression rates to vary according to race and ethnicity groups and SES. Caucasian mothers were more likely to meet criteria (9.3%) than other groups (ranging from 4.3% to 4.6%) and more mothers of lower SES met depression criteria (7.6%) than mothers in the higher SES groups (5.3%).

The second research question specifically looked at the association between maternal depression and parent identification of special needs, finding that mothers with depression were more likely to report their child had special needs. This finding is somewhat surprising based on other research suggesting less frequent access to

health services among mothers with clinical depression, and impaired functioning as an essential feature of clinical depression. Most of the symptoms of depression reflect an inhibition of actions (e.g. losing interest, trouble concentrating, feeling tired, etc.) which do not seem consistent with these findings. Additional analyses did confirm that women with depression were reporting significant impairment, with 59% of the mothers with depression reporting that “sad or blue” feelings interfered “a lot” with their everyday life and activities, providing some evidence for the level of severity of depression among the group.

One possible pathway through which mothers with depression may have an increased likelihood of having been informed by a physician that the child has a special need is through their own involvement in the medical system. The additional analyses showed that a large number of the depressed women reported that they sought help for their symptoms, including treatments of counseling and medication. It is possible that they were getting family-level intervention and support as part of their treatment. For example, mental health or medical providers assessing depression might be more likely to assess family stresses associated with parenting and family relationships that might be contributing factors to the depression. It may be that these mothers are more likely to have an opportunity to express concerns about their child in this context, and subsequently receive support and direction for addressing these concerns. This might lead to the mother (or health care provider) pursuing an evaluation of the child by a physician or developmental specialist. Mental health professionals treating a parent with depression may also be aware of and concerned for the child’s well-being, considering the seriousness of the

symptoms of clinical depression and the potential additional stressors associated with the care-giving role.

Additional analyses looked at the number of pediatric visits the parent and child had for well-child checkups, a primary avenue through which a child's development is assessed and through which referrals for additional evaluation are made. Results show that mothers with depression took their child to significantly more well-child visits than mothers without depression. It may be that mothers with depression are more vigilant about seeking medical care for their child out of a heightened concern that her own mental health status may negatively influence the child's development. This trend might also be reflecting a more generalized pattern of help-seeking among mothers with depression, which encompasses the family system as well.

The final research question assessed the relationship between maternal depression and children's receipt of services. Among all the children that had developmental delays of various level of severity, just 6.9% were receiving at least one special service (speech-language therapy, hearing services, etc.). Paralleling the previous results, analyses of this question also showed a differential association by depression; mothers with depression were more likely to report that their child was receiving early intervention services than mothers without depression. The rates of service receipt, while significantly different in the two groups, are low among both- 8% among children of mothers with depression, and 5.7% among children of mothers without depression. Two research studies using the ECLS-B data have examined similar questions on receipt of early intervention services. Rosenberg et al

(2008) found the rate of early intervention services to be somewhat higher than this study, reporting 10% of children with developmental delays receiving services at age two. Rosenberg's study used a universal cutoff using the two Bayley sub-scales (two scores ≥ 1.0 SD below the mean or one score ≥ 1.5 SDs below the mean), and classified children born at very low birth weights as having developmental delays. Feinberg, Silverstein, Donahue, & Bliss (2011) also reported a higher rate of service receipt of 12%. Feinberg et al included genetic and medical conditions, birth weight $< 1000\text{g}$, and Bayley scores (two scores ≥ 1.0 SD below the mean or one score ≥ 1.5 SDs below the mean) to classify developmental delay. The lower percentage of children receiving services in the current study (6.9%) is likely due to the omission of conditions identified at birth and infancy, as well as the omission of low birth weight infants. In addition, the above two studies used a universal cutoff that was on the lower end (i.e. less restrictive) of the range seen among states and used to estimate eligibility in the current study.

Both Feinberg et al (2011) and Rosenberg (2008) found black children received services at significantly lower rates compared to white children. Among the more restrictive sample used in the current study, black children were not represented among those receiving services, so estimates could not be generated. However, among a combined group of minority children (including multi-race, Asian, and American Indian/ Alaska Native), the rate of services was 2.4%, compared to 10% among Caucasian children. Again, while there are disparities in receipt of services based on race and ethnicity groups, it may be argued that all groups are under-served: among the group of children being served at the highest frequency

(Caucasian children), the highest sub-group rate is still only 10% of eligible children getting intervention services. Nevertheless, this pattern of differential service delivery for other than Caucasian children is a national trend that the service delivery system needs to address.

In summary, among children with developmental delays in the current study, rates of mothers' identifying their children's delays were generally low for all, and they had corresponding low rates of receiving early intervention services. Mothers reported seeing physicians for well-child visits, but did not report that their children's delays were identified by these physicians or others. Maternal depression was found to be positively associated with both parent report of children's disability and receipt of early intervention services for the child, with these mothers more likely to identify the child's impairment(s), and more likely to have their child in services. Descriptive analyses of these mothers' responses showed that although they were reporting significant impairment associated with depressive symptoms, they were also successfully navigating the early intervention system from referral to eligibility determination to implementation of services for their children, and seemed to be accessing health services for themselves. The findings of increased identification of disabilities and increased service utilization may reflect a pattern of help-seeking behavior that is more pronounced among mothers with depression.

Limitations

This section briefly describes several important limitations to the current study, including those related to specific variables used and limitations based on the ECLS-B structure. First, the eligibility sample used in the current study, while tailored

to the criteria in the state the child lived in, only approximates eligibility. It is not an exact representation of which children would have been found eligible through a team process conducted in their local districts, even if done at the same time as the ECLS direct assessments were completed. Assessment during early childhood, particularly with toddlers, presents many challenges and inevitable variability, even with the use of standardized tools, administration protocols, and well-trained assessors. The specific tools used among states vary widely, and may not yield scores comparable to the Bayley; it is likely that some children included in the study sample would not be found eligible in their state while others excluded from the sample might be found eligible. Further, children were grouped together in the sample used for this study. Although severity of disability was used as a control variable, the current study did not examine subgroups of children based on their specific eligibility profile (e.g. in which domain they met eligibility). It is possible that different patterns would emerge based on a more in-depth look at additional eligibility variables.

Another consideration related to eligibility concerns the Bayley sub-scales used as part of the sample creation. Because only two of the traditional domains of the Bayley (motor & cognitive) are used as part of a standardized assessment measure for eligibility, relying solely on these two sub-scales may under-estimate the population of children eligible. For example, a child with a significant delay on a standardized measure of social-emotional functioning might be determined eligible for early intervention services based primarily on this criterion. However, unless this

child also had delays in cognitive and/or motor functioning, s/he would be excluded from the current study sample.

A third limitation is that many states allow eligibility determination based on qualitative assessment practices. Children may become eligible through these pathways who demonstrate atypical behavior without a corresponding delay on standardized assessment instruments (Shakelford, 2006). In addition, eligibility determination is required to include clinical opinion for Part C services (see 34 CFR 303.322(c)(2)) (Shakelford, 2006). For the current study, states that reported only clinical opinion were grouped with states using a somewhat more lenient cutoff for eligibility (1.5 SD below the mean in at least one area). In practice, it is likely that there is variability of implementation of a qualitative standard such as “informed clinical opinion” based on local program factors and the expertise and professional background of the eligibility team. It is also possible that this qualitative component of eligibility determination sometimes results in determining a child is eligible, and in other cases contributes to a determination the child is not eligible for Part C services. Therefore, it is difficult to precisely identify eligible children from these states, and aspects of clinical judgment may alter the representation of other children’s eligibility as well. Eligibility determination done by local early intervention professionals and teams may also differ in other qualitative ways from the approach used in the current study in that local teams should use multiple sources of information beyond standardized assessment scores. These might include parent, teacher and other caregiver report, observation, and clinical expertise.

One final limitation related to eligibility is that the current study used eligibility criteria for Part C services, but services received may or may not have been provided through Part C. Although questions were asked about the provider of services (school district, health department, private doctor, etc.) these do not inform whether services were or were not provided as IDEA Part C services. States vary widely in the implementation of Part C; lead agencies primarily include departments of public health and/or education, but also include human services, social welfare, and rehabilitation or developmental disabilities departments, among others (see <http://www.nectac.org/partc/ptclead.asp> for a current list). In addition to the variability among lead agencies, states vary in their service delivery models, specific services covered, amount of services covered, and parent payment or co-payment for services. For example, the most frequently reported service, speech and language therapy, might be provided in the home, at childcare, or in a clinic setting; these service settings might be part of a school, social services agency, or health department-led program, and may or may not be paid for by Medicaid, private insurance, or parent fees. Ultimately, it is unclear whether all the services reported were part of the Part C service delivery system in that state.

The current study also has limitations with respect to the measurement of depression. The depression status of mothers was defined at the time when the child was age two. This time point was chosen over measures of depression at the nine-month age group to limit over-estimates of depression related to the postpartum period. While rates of depression among the mothers in the current study were comparable to rates in other studies, mental health indicators may have been under-

or over-reported in the context of reporting in the ECLS-B study. Rates of depression may also vary from rates in the larger population including mothers who self-selected not to participate in the ECLS study. Additional limitations exist regarding the quality of the maternal depression tool used and the measurement of the severity of depression. While the CIDI is a commonly used tool for research and screening, there are limitations in that the measure was self-administered, and there was no verification of the classification of women as meeting clinical depression criteria (e.g. through a clinical interview by a licensed mental health or medical professional). Further, it was not possible to verify or quantify treatment for depression (e.g. counseling, medication) reported by mothers in order to further examine differences in the type or amount of intervention for mothers' depression. These factors may be related to the mother's access or timing of services for their children. Finally, differences by race/ethnicity were not further explored due to limitations in the available data in that sample sizes among some race/ethnicity subgroups were small.

Importance and Future Research

Findings from this research study add to knowledge about the characteristics of children and families being served in early intervention in the U.S. They add to other research findings highlighting the discrepancies between the numbers of young children in need and the numbers accessing services, and help identify differential rates of services among developmentally delayed children. Specifically, the current research found that children in families in which the mother had clinical

depression in the previous year were not among the subgroups of children served at lower rates.

The current study adds to other national studies reporting service patterns in early intervention, and provides a unique additional perspective by addressing pathways of services among children who were not identified during infancy or in the first year of life. In addition, the current study is unique in its use of state-specific criteria rather than a universal cutoff score to estimate which children are eligible for early intervention. Despite some limitations of this approach as discussed above, this method more accurately reflects the diversity of states' eligibility criteria, and the presumption that children are eligible prior to determining their service receipt yields a more specific population estimate.

However, the current study does little to illuminate the direction of the relationship of mothers' mental health issues with children's disabilities, and only hints at the pathways through which this relationship might be occurring. The reciprocal nature of child development processes, parent-child interactions, community factors such as service resources and pediatric support, and biological processes such as depression and disability make causal pathways inherently difficult to disentangle.

Child find efforts nationally must re-evaluate their current rates of service delivery, and evaluate system capacity to dramatically expand services to more children, especially minority children and families. Some improvements would necessitate societal-level policy or program mandates to improve access, some of which may be difficult to enact and enforce from political and public funding

perspectives. For example, for Part C to serve all young children showing developmental delay using similar criteria to the current study, a conservative estimate would have the program expanding ten times of its current level. This unlikely scenario would not play out without dramatic changes to the current system, including ongoing evaluation of the evidence base documenting improved child outcomes resulting from receipt of early intervention services.

Future research building on the current study includes longitudinal follow-up of the sample children that did and did not enter into early intervention services, and comparisons of outcomes of children of mothers with and without depression. Child outcomes might include looking at improved performance on the direct child assessments, improved parent-child interactions, or special education placements in preschool and kindergarten. Investigation of maternal outcomes would inform whether there are improved family-level outcomes for mothers whose child participated in early intervention; these might include maternal health, mental health, or social-emotional measures such as reduced parenting stress, improvements in parent-child interactions or partner relationships. Follow-up research about other parent and family characteristics of children who did enter services may offer insights into subgroups that are accessing services at greater rates. Another area of further study might look at maternal-child interaction measures among mothers with and without depression. Finally, future research that would expand findings from this study should include an in-depth study of barriers in the referral and eligibility processes of the early intervention service systems for parents with different social

health characteristics. This avenue of research may benefit from the inclusion of qualitative methodologies to inform future large-scale studies.

In conclusion, the study findings emphasize that there are disparities in access to early intervention services; young children with developmental delays are under-identified and under-served. Nationally we have a commitment to serving children with disabilities, as evidenced through continued reauthorization of legislation such as IDEA, including services to infants and toddlers with disabilities served through the Part C program. States are also required to track and report the number and percent of children served through early intervention services, and to report on child find policies and activities in their state as part of ongoing federal accountability processes. Despite these measures, there is clearly a widespread national problem in that young children with delays are not getting needed timely intervention services. Additional research evidence may be instrumental in informing policy decisions related to funding Part C and other early childhood special education programs. It is also likely that advocacy, program and policy evaluation, and multiple avenues of change are needed to reverse the current trend of limited services and service inequalities, towards improving the outlook for the futures of young children with developmental delays and disabilities.

APPENDICES

Appendix A: Table of Variables

Construct	Question wording/ source of information	Variable Name
Disability reported at nine months (<i>excluded cases</i>)	Has a doctor ever told you that (child) has the following conditions? a) Blindness b) Difficulty seeing, including nearsightedness or farsightedness, c) Difficulty hearing or deafness d) Cleft lip or palate? e) A heart defect? f) Failure to thrive? g) Problem w/mobility or using legs? h) Problem w/using his/her arms? i) Down Syndrome? j) Turner's syndrome? k) Spina Bifida? l) Any other types of special needs or limitations?	CH 165 a-l
Birth weight (<i>other than normal weight excluded</i>)	Birth weight taken from birth certificate (grams).	X1CHPREM
Prematurity status (<i>fewer than 37 weeks excluded</i>)	Pregnancy gestation taken from birth certificate and confirmed by parent at nine month interview (number of weeks of pregnancy).	X1BTHWGT
Bayley t-scores: mental and motor sub-scales	Sub-scores of two Bayley scales	X2MTRTSC X2MTLTSC
State of residence	FIPS code for state of residence.	P2CSTATE FIPS at time 2, FIPS @ T2
Outcome variables		
Outcome variable: Parent awareness of child's disability	Has a doctor ever told you that (child) has the following conditions? Does he/she have... a) Blindness b) (<i>not included: difficulty seeing, including nearsightedness or farsightedness?</i>) c) (<i>not included: crossed eye, or a lazy or wandering eye?</i>) d) Difficulty hearing or deafness (do not include temporary loss of hearing due to cold or congestion) e) A problem with mobility such as cerebral palsy? f) A delay in learning to walk? g) A delay in learning to talk? h) Another developmental delay? i) (<i>not included: epilepsy or seizure disorder</i>) j) (<i>not included: lactose intolerance</i>) k) Mental retardation? l) (<i>not included: food allergies or sensitivities</i>)	CH 180 a, d, e, f, g, h, k

Construct	Question wording/ source of information	Variable Name
Receipt of early intervention services	Is (child) currently participating in an early intervention program or regularly receiving any services for her/his condition(s) from... a) Your local school district? b) A state or local health or social service agency? c) A doctor, clinic, or other health care provider? d) Some other source?	CH 195 a-d
Receipt of early intervention services	There are services available to families with children who may have special needs. For example, parents may seek language or physical therapy for their children. They may place their children in special classes with other children who have similar needs, or they may seek support or training for themselves. Does (child) or your family receive any services to help with special needs that child may have?	CH 184
Receipt of early intervention services	[If yes to CH 184] I'm going to read a list of services. For each service, please tell me if (child) or your family received this service to help with (child's) special needs. Since our last interview in (time frame) has anyone in your household ever received... a) Speech or language therapy? b) Occupational therapy? c) Physical therapy? d) Vision services e) Hearing services f) Social work services? g) Psychological services? h) Home visits? i) Parent support or training? j) Special classes with other children some or all of whom have special needs?	CH 185 a-j
Services received	[If yes to any services]: About how many hours of service per month are received? <i>Probe: if more than one service is received, tell me the total number of hours per month for all services.</i>	P2SRVHRS (number of hours)
Access to health care	How many well-child visits have you had since (last interview)	CH 175
Covariates		
Maternal Depression	Since our last interview in (time frame) was there ever a time when you felt sad, blue, or depressed for two weeks or more in a row? (<i>Skip pattern: yes moves on to part 1 of depression scale</i>)	FH 090 P2FLTSAD

Construct	Question wording/ source of information	Variable Name
Maternal Depression	Depression scale items administered based on FH 090	P2BLUAD; P2EBLADY; P2ELSINT to MD_A1C (RECODE) P2ELSENG to MD_A1C (RECODE); P2EWGTCG; P2EAMTCG; P2ETR BSP; P2ETRSP; P2ETRBCN; P2EWRTLH; P2EDEATH; P2EWKBLU; P2ELSTBL
Maternal Depression	Did you tell a doctor about these problems?	FH 160
Maternal Depression	Did you tell any other professional (SW, psychologist, nurse, clergy, etc)	FH 165
Maternal Depression	Ever took medication?	FH 170
Maternal Depression	How much did these probs interfere w/life activities? (lot little, some, etc.)	FH 175
Family health	In general would you say your health is...excellent/ good/ very good/ fair/ poor	P2HEALTH
Family health	Does anyone in your household have a special need, delay, or disability? (<i>Other than child, if child identified</i>):	P2HHNEED
Mental health-help seeking	In the past 12 months, have you talked with a psychiatrist, doctor or counselor for any emotional or psychological problem? (FH060)	P2TKPSYC

Appendix B: Demographic Tables with Confidence Intervals

	Sample		Population	
	Weighted N*	Percent (95% CI)	Weighted N*	Percent (95% CI)
Child characteristics				
Child gender				
<i>male</i>	190,600	63.49% (63.32-63.66)	2,031,800	51.23% (51.19-51.28)
<i>female</i>	109,550	36.49% (36.32-36.67)	1,933,900	48.77% (48.72-48.81)
Child's Race/ Ethnicity				
<i>White/ non-Hispanic</i>	121,300	40.41% (40.2- 40.6)	2,118,300	53.55% (53.50-53.60)

	Sample		Population	
	Weighted N*	Percent (95% CI)	Weighted N*	Percent (95% CI)
<i>Hispanic, any race</i>	117,050	38.99% (38.82-39.17)	1,000,350	25.29% (25.25-25.33)
<i>Black or African American</i>	33,700	11.23% (11.11-11.34)	541,400	13.65% (13.62-13.69)
<i>More than one race, non-Hispanic</i>	14,300	4.76% (4.69-4.84)	159,600	4.02% (4.01-4.04)
<i>Asian</i>	11,150	3.71% (3.65-3.78)	107,200	2.70% (2.69-2.72)
<i>American Indian/ Alaska Native</i>	2,100	0.70% (0.67-0.73)	20,450	0.52% (0.51-0.52)
<i>Pacific Islander/ Native Hawaiian</i>	550	0.18% (0.17-0.20)	8,300	0.21% (0.20-0.21)
Birth weight				
<i>Normal weight (>2500g)</i>	300,200	100%	3,666,750	92.50% (92.48-92.53)
<i>Birth weight below 2500 g</i>	n/a	n/a	297,200	7.5% (7.47-7.52)
Prematurity				
<i>Full term (40 weeks or more)</i>	280,200	93.34% (93.25-93.43)	3,457,300	87.18% (87.15-87.21)
<i>One week preterm (39 weeks)</i>	8,500	2.83% (2.77-2.89)	167,050	4.21% (4.19-4.23)
<i>Two weeks preterm (38 weeks)</i>	6,050	2.02% (1.97-2.07)	103,550	2.61% (2.60-2.63)
<i>Three weeks preterm (37 weeks)</i>	700	0.23% (0.22-0.25)	63,900	1.61% (1.60-1.62)
<i>Not ascertained</i>	4,750	1.58% (1.54-1.63)	48,300	1.22% (1.21-1.23)
<i>More than three weeks preterm</i>	n/a	n/a	125,600	3.17% (3.15-3.18)
Multiple birth status				
<i>Singleton birth</i>	295,550	98.45% (98.41-98.5)	3,832,450	96.82% (96.80-96.85)
<i>Twin in household</i>	4,550	1.52% (1.47-1.56)	119,050	3.0% (2.99-3.02)
<i>Higher order multiples</i>	n/a	n/a	7,100	0.18% (0.18-0.18)
Child's overall health				
<i>excellent</i>	162,800	54.23% (54.05-54.41)	2,441,350	61.56% (61.51-61.61)
<i>very good</i>	87,500	29.14% (28.98-29.31)	1,052,250	26.5% (26.49-26.58)
<i>good</i>	43,400	14.46% (14.33-14.58)	386,950	9.76% (9.73-9.79)
<i>fair/poor</i>	6,450	2.15% (2.10-2.20)	84,400	2.13% (2.11-2.14)
Place for well-baby check ups				
<i>Doctor's office or HMO</i>	200,400	66.76% (66.59-66.92)	2,954,500	74.50% (74.46-74.54)

	Sample		Population	
	Weighted N*	Percent (95% CI)	Weighted N*	Percent (95% CI)
<i>Health center or clinic</i>	85,250	28.40% (28.24-28.56)	894,200	22.55% (22.51-22.59)
<i>Hospital outpatient or Emergency room</i>	4,500	1.50% (1.46-1.54)	47,400	1.20% (1.18-1.21)
<i>Not applicable</i>	10,050	3.35% (3.28-3.41)	64,250	1.62% (1.61-1.63)
<i>Other place or no regular place</i>	0	0%	4,500	0.11% (0.11-0.12)
Number of well-baby checks	mean	range	mean	range
	2.9 visits	0-20	2.9 visits	0-20
Developmental Status	mean	range	mean	range
<i>motor t-score</i>	33.98	3-67	50.0	3-97
<i>cognitive t-score</i>	36.55	15-73	50.0	15-88
Maternal characteristics				
Maternal education (highest completed)				
<i>Some high school or below</i>	106,050	35.33% (35.16-35.50)	1,070,250	27.10% (27.06-27.15)
<i>High school diploma or equivalent</i>	63,150	21.04% (20.89-21.08)	851,800	21.57% (21.57-21.61)
<i>Some college or vocational/ technical</i>	76,050	25.33% (25.18-25.49)	1,049,900	26.59% (26.54-26.63)
<i>Bachelor's degree or higher</i>	54,950	18.30% (18.17-18.44)	976,850	24.74% (24.70-24.78)
Mother's age				
<i>Ages 17-24</i>	88,550	29.50% (29.33-29.66)	1,012,400	25.64% (25.59-25.68)
<i>Ages 25-34</i>	149,400	49.77% (49.59-49.95)	2,033,200	51.49% (51.44-51.54)
<i>Age 35 and older</i>	62,250	20.74% (20.59-20.88)	904,900	22.92% (22.87-22.96)
	mean	range	mean	range
<i>Mothers age overall</i>	29.0 years	17-47	29.5 years	17-70
Respondent marital status				
<i>Married</i>	186,500	62.13% (61.95-62.30)	2,687,650	67.79% (67.74-67.84)
<i>Separated/ divorced/ widowed/ never married</i>	113,700	37.87% (37.70-38.05)	1,277,000	32.21% (32.16-32.26)
Respondent's country of birth				
<i>United States</i>	203,500	67.79% (67.62-67.96)	3,146,800	79.37% (79.31-79.39)
<i>US Territories or another county</i>	96,650	32.20% (32.03-32.36)	818,200	20.63% (20.59-20.67)
Respondent's primary language				
<i>English</i>	209,300	69.8% (69.72-69.88)	3,244,000	81.78% (81.75-81.82)

	Sample		Population	
	Weighted N*	Percent (95% CI)	Weighted N*	Percent (95% CI)
<i>Another language</i>	90,900	30.2% (30.12-30.44)	721,000	18.18% (18.14-18.22)
Respondent's overall health				
<i>excellent</i>	87,000	28.98% (28.82-29.14)	1,331,400	33.57% (33.52-33.61)
<i>very good</i>	98,650	32.86% (32.69-33.03)	1,380,400	34.80% (34.75-34.85)
<i>good</i>	87,600	29.18% (29.02-29.34)	930,300	23.45% (23.41-23.50)
<i>fair/poor</i>	26,950	8.98% (8.88-9.08)	322,250	8.18% (8.16-8.21)
Household Characteristics				
Parents residing in household				
<i>Biological mother and any father type</i>	222,450	74.10% (73.94-74.26)	3,115,000	78.55% (78.51-78.59)
<i>Biological mother only</i>	77,750	25.90% (25.74-26.06)	793,250	20.00% (19.96-20.04)
<i>Other (e.g. father only, adoptive parents, guardian(s))</i>	n/a	n/a	51,900	1.44% (1.42-1.47)
Socioeconomic scale (quintiles)				
<i>Lower two quintiles</i>	147,600	49.18% (48.99-49.35)	1,584,200	39.94% (39.90-40.0)
<i>Upper three quintiles</i>	152,550	50.82% (50.64-51.00)	2,381,500	60.05% (60.0-60.10)
Anyone in household with special need? (other than focal child)				
<i>Yes</i>	35,900	11.96% (11.84-12.08)	342,450	8.64% (8.61-8.66)
<i>No</i>	264,250	88.04% (87.91-88.14)	3,621,750	91.36% (91.32-91.39)

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